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Summary: August, 2006. A LOOK AT TBI TRUST FUND PROGRAMS: Possible Funding Sources for Helping Individuals and Their Families Cope with Traumatic Brain Injury

A LOOK AT TBI TRUST FUND PROGRAMS

What are TBI Trust Funds?

Trust funds are accounts established by law and earmarked for specific purposes. As State revenue sources become more difficult to obtain, TBI trust funds offer an additional way to serve individuals who have sustained a traumatic brain injury. The earliest TBI trust fund legislation occurred in 1985 in Pennsylvania. Today, there are 19 fully operational trust fund programs throughout the United States, ten of which also benefit individuals with spinal cord injuries. Two additional programs are under development in Montana and Connecticut.

While all the programs are not specifically called “trust funds,” they do share these similarities:

- They are established by legislation and dedicated for activities benefiting individuals with brain injury.
- They are supported by revenues from a fee, fine, or surcharge.
- Revenue is placed in an interest-bearing, non-reverting account.

How do they work?

Despite the fact that a trust fund is an account dedicated for a specific purpose, many States require legislative approval to use TBI funds. Gaining this approval involves establishing an annual budget and presenting it before a budget or finance committee in the General Assembly.

Estimated revenue varies widely for established programs, from less than \$1 million to \$17 million. The average is between \$1 million and \$4 million annually. The sources of revenue also vary but are most often tied to traffic offenses—a leading cause of car crashes and TBI.

Just as revenue for trust funds varies, so do their uses. Many programs provide funding for individual consumer needs while others devote funds to projects selected through a request for proposal (RFP) process. Some combine trust fund monies with general revenue or other sources to support new or existing programs, promote research, or help fund registries, information and referral, education, prevention, resource coordination, grants, or waivers. In at least one State, a portion of trust fund monies was used to match the Health Resources and Services Administration's (HRSA) Federal TBI Grant Program grant project. In another, trust fund monies help sustain programs started with HRSA grant funds.

While there may be no direct relationship between the HRSA Federal TBI Grant Program and the evolution of TBI trust fund programs, the increase in exchange of information between States has most likely stimulated interest in their development. For some States, the Federal program also provides for the continued presence of an individual or advisory body able to initiate development of such a fund when the time is right.

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How do you establish a trust fund?

Development of a TBI trust fund is one avenue for States to explore as they work towards expanding resources and achieving comprehensive systems of services and supports. But getting a trust fund established is not without challenges. At least one State was successful in getting legislation approved to establish a trust fund but has no approved mechanism for generating revenue. Others have experienced difficulty in getting legislative support for a trust fund because their legislators view any fee, fine, or surcharge as a tax, with the legislature being committed to no new taxes. In one State, a change in its Constitution is required in order to share revenues from fees, fines, or surcharges with public education initiatives. See document *Compilation of TBI Trust Fund Legislation* (included in this binder and available from the Traumatic Brain Injury Collaboration Space at <http://www.tbic.nashia.org/tbics>) for sample legislation.

Because political climates and priorities differ from State to State, there is no "one size fits all" strategy for establishing and operating a trust fund. However, some common insights have emerged:

1. A strong, statewide grassroots advocacy effort (typically led by the Brain Injury Association of America's chartered State affiliate) is critical in laying the groundwork for legislation. This includes getting buy-in not only from legislators but also from stakeholders, such as 1) agencies that will be facilitating revenue collections, and 2) top management at the agency that will administer the program.
2. One or more powerful legislators are needed to champion the bill.
3. Judges, court clerks, department of motor vehicles, or whoever is critical to the revenue collection process, must be educated about the legislation and its importance so that they will willingly fulfill their collection obligation.
4. Expect the start-up process to take one to two years. The start-up process often includes time for the collections process to begin generating sufficient monies;

setting up an advisory board if one does not already exist; finalizing priorities and operating procedures; promulgating administrative rules; and allowing contract bids or placing additional staff as needed.

5. Make sure the rules are clear so they are not misinterpreted by individuals who stand to benefit from the program nor those who administer it. Keep them flexible enough to allow for the unexpected.

6. Anticipate as much as possible, but expect change. Only through experience will a State know what works and what does not work.